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SCIENCE SPOTLIGHT

A pathway to enriching the PCDC with real-world treatment data

The paper: Furner B, Cheng A, Desai AV, Benedetti DJ , Friedman DL, Wyatt KD, Watkins M, Volchenboum SL, Cohn SL. **Extracting Electronic Health Record Neuroblastoma Treatment Data With High Fidelity Using the REDCap Clinical Data Interoperability Services Module.** *JCO Clin Cancer Inform.* 2024 May. doi: 10.1200/CCI.24.00009

The research: In this study, we explored a method for extracting real-world treatment data from electronic health records (EHRs) of children with neuroblastoma using the REDCap Clinical Data Interoperability Services (CDIS) module. This tool provides seamless data exchange between any EHR system with a Fast Healthcare Interoperability Resource (FHIR) API and REDCap. The FHIR standard represents EHR data in an interoperable way, making it possible to share health information electronically regardless of the EHR.

The aim of the pilot study was to determine the feasibility of using the REDCap CDIS module to extract chemotherapy and immunotherapy treatment data from the EHRs of neuroblastoma patients. Our long-term goal is to accelerate neuroblastoma research by enriching the INRG Data Commons, which is part of the Pediatric Cancer Data Commons (PCDC), with real-world data extracted from EHRs.

For this proof-of-concept study, we used REDCap CDIS to pull treatment data directly from Epic via FHIR endpoints. We extracted chemotherapy and immunotherapy drug orders for patients enrolled in a Children's Oncology Group neuroblastoma biology study at two medical centers, then validated the accuracy of extracted data by comparing it with data obtained from the medical centers' institutional EHR relational databases and manual chart review. Our results showed that this extraction method performed with a high degree of accuracy, with more than 99% of the chemotherapy and immunotherapy drug orders in the EHR relational databases identified in the corresponding CDIS output.

Why it matters: A pathway for the automated extraction of treatment data from EHRs creates the possibility of enriching the data in the PCDC and other data commons with real-world treatment data. These real-world data, which traditionally have only been obtainable through time-consuming and error-prone manual chart review, include valuable information about routine clinical care that is not captured in data from clinical trials. Although the retrospective data already in the PCDC has enabled numerous discoveries, including these real-world data would significantly increase the types of meaningful research that the commons can support, especially when it comes to understanding the impact of specific therapeutics on patient outcomes.

Thanks to the interoperability of the FHIR standard and the ubiquity of REDCap, this solution is scalable far beyond this initial study. We are now in the process of expanding our pilot to include additional clinical sites, EHR vendors, and eventually other data types and diseases. With wider implementation, this approach will make it easier for EHR data to be extracted and included in data resources, enrich the data in the PCDC, and facilitate research that could lead to new treatments and better outcomes for patients.

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